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A mixed-methods exploration of the contraceptive experiences of female teens with epilepsy

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ABSTRACT

Purpose: We explored the contraceptive experiences of female teens with epilepsy, including their knowledge and perceptions of interactions between antiepileptic drugs and hormonal contraception and contraceptive decision-making processes.
Method: From November 2012 to May 2013, we conducted one online survey ($n = 114$) and 12 online focus group discussions ($n = 26$) with female teens with epilepsy about their contraceptive experiences and unmet needs. Survey data were analyzed using descriptive statistics and focus group transcripts were analyzed thematically using modified grounded theory methods.
Results: Both survey and focus group participants reported believing that interactions between epilepsy medications and hormonal contraceptives could lead to reductions in contraceptive efficacy and seizure control. However, their knowledge about these types of medication interactions was often incomplete. Many study participants viewed contraceptive decision making as a difficult process, and some participants reported avoiding hormonal contraceptives because of potential interactions with antiepileptic drugs. Study participants reported relying on health care providers and parents for contraceptive decision-making support. Focus group participants also reported they wanted health care providers to provide more in-depth and comprehensive counseling about contraception, and that they desired peer support with contraceptive decisions.
Conclusion: The ability to make informed contraceptive decisions is important for teens with epilepsy as interactions between anti-epileptic drugs and hormonal contraceptives can impact seizure occurrence and lead to an increased risk of unplanned pregnancy. Guidance for providers offering contraceptive care to this population is needed, as well as a contraceptive support tool that empowers teens with epilepsy to advocate for desired health care.
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1. Introduction

Epilepsy is a common, chronic, and often stigmatized neurological condition characterized by recurrent, unpredictable seizures. Seizures can be triggered by flashing lights, noise, stress, hormonal shifts, and other events. The primary treatment for epilepsy is antiepileptic drugs (AEDs), which stop or reduce seizures in approximately 70% of people. Adjunctive or alternative treatments can be used in those with refractory seizures.[1]

Over one million women and girls in the United States have epilepsy and require specialized contraceptive care due to potential interactions between AEDs and hormonal contraceptives.[2] These medication interactions can lead to reductions in the efficacy of hormonal contraceptives, putting women at increased risk of unplanned pregnancy.[3] Unplanned pregnancy is of particular concern in this population as hormones brought about by pregnancy can impact seizure frequency and AED use during pregnancy can double the risk of fetal anomaly.[4] Further, medication interactions can lead to increased seizure activity,[5] increasing the risks of morbidity and mortality and decreasing quality of life.[1] At the same time, some limited research suggests that hormonal contraceptives that keep hormones in a steady state can help alleviate hormonally induced seizures.[6]

Despite the serious implications of drug interactions, research shows that adult women with epilepsy are largely unaware of interactions between AEDs and hormonal contraceptives and face challenges obtaining accurate information about them.[7–9] Several studies have found that most women with epilepsy have never received information about medication interactions[8–11] and that health care providers working with this population have limited knowledge about their contraceptive needs.[8,12–17] Given these challenges, it is unsurprising that women with epilepsy have lower

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rates of highly effective contraceptive use compared to the general population.[18]

There is a dearth of research investigating if female teens with epilepsy experience the same challenges accessing appropriate contraceptive care as their adult counterparts. While many teens, regardless of health status, experience difficulties accessing high-quality contraceptive care,[19] data indicate that teens with chronic health conditions are less likely to receive information about sexual and reproductive health from their health care providers.[20] Further, despite going to the doctor more often than the general population, teens with chronic health conditions are less likely to receive high-quality health care.[21]

Given that adolescence is a sensitive developmental period, that teens with chronic health issues face barriers accessing high-quality contraceptive care,[20,21] and that contraceptive use among teens with epilepsy has serious implications for neurological and reproductive health, investigation into their contraceptive experiences is necessary. Additionally, as more people in the United States (US) take prescription medications for chronic health conditions, issues related to medication interactions are increasingly relevant for a larger population. To date, no identifiable study has investigated the contraceptive experiences of female teens with epilepsy. To fill this gap in the literature, we conducted an online survey and online focus groups with female teens with epilepsy to better understand their: (1) knowledge and perceptions of interactions between AEDs and hormonal contraception; (2) contraceptive decision-making and experiences; (3) contraceptive supports; and (4) recommendations for improving contraceptive service-delivery.

2. Materials and methods

A two-step, mixed-methods study was selected for this investigation to allow for the development of a rich and nuanced understanding of the contraceptive needs of teens with epilepsy. The first phase of the study, conducted from November 2012 to December 2012, consisted of an online survey with female teens with epilepsy. The second phase of the study, conducted from January 2013 to May 2013, consisted of online focus group discussions with female teens with epilepsy. The study was approved by the Allendale Investigational Review Board.

Both phases of the study were conducted online and used Facebook as a recruitment method. These online research methods were selected because 95% of US teens use the Internet[22] and 73% use Facebook.[23] Further, among qualitative methods, online, chat-based focus groups were selected because the method has been shown to reach hard-to-reach populations, be preferable for teens, and facilitate disclosure of sensitive information.[24–27] The number and role of the moderators, focus group ground rules, and focus group program and features were informed by research showing best practices in online focus group research.[25,26,28–32] Additionally, focus groups were limited to three participants, as previous research has shown that smaller group size is easier to manage online while still encouraging rich discussion.[25]

Participants in both phases of the study were asked questions about their epilepsy history; dating experiences; contraceptive and pregnancy history and experiences; knowledge and perceptions about contraceptive and pregnancy issues for females with epilepsy; and preferences for decision-making support around contraception and pregnancy. This analysis focuses on the contraceptive findings.

For the online survey, a convenience sample was recruited through Facebook advertisements and online youth- and epilepsy-focused Facebook groups. Female teens; diagnosed with epilepsy; age 13–19 at the time of initial contact; fluent in English; and who, if younger than 18, had previously sought contraception or experienced pregnancy in one of the 25 US states where minors who have sought contraception or experienced pregnancy can participate in research without parental consent, were eligible to participate.[33] To ensure that the individuals did not take the survey multiple times, we removed responses that came from duplicate IP and email addresses, and had the exact same survey responses, especially to open-ended questions.

Prior to proceeding to the online survey, participants were asked several questions assessing their eligibility, and, if eligible, were asked to give electronic informed consent to participate. All participants were provided with a $15 gift card for remuneration. As the survey was exploratory, no power calculation was conducted to determine the number of survey participants. Instead, we recruited as many survey participants as feasible given our time and budget limitations.[34]

Survey data were exported from the online survey into Excel and then into SPSS. In SPSS, basic descriptive statistics, cross tabulations, and measures of association were performed. Answers to open-ended questions were exported into Word and analyzed thematically.

For the online focus groups, a convenience sample was recruited via Facebook advertisements, online youth- and epilepsy-focused Facebook groups, and an epilepsy forum on Reddit. In addition, survey participants were encouraged to participate in the online focus groups. Eligibility criteria for the online focus groups were the same as the online survey. Prior to entering the online focus groups, teens filled out a brief survey assessing their eligibility, and gave electronic informed consent to participate. All participants received a $40 gift card as remuneration. Focus group participants were recruited until thematic saturation was reached.[35]

Online focus group discussions were conducted through Chatzy, a private, password-protected, online chat service. Two research team members, trained in qualitative research methods, served as moderators during the focus groups. Moderators typed questions into the chat room and participants typed responses; no video or audio technology was used during the focus groups. Participants were also encouraged to respond to each other's comments and to ask each other questions.

Focus group transcripts were populated in the chat program. We exported the transcripts and then analyzed thematically in ATLAS.ti 6.2 (Scientific Software Development, Berlin, Germany) using modified grounded theory methods.[36] Two researchers coded each transcript to ensure inter-coder reliability. Initial codes were developed a priori based on focus group questions and subsequent revisions were made to the codebook as new inductive themes surfaced. Codes were summarized and organized thematically with representative quotes extracted. Illustrative quotes were identified for all major themes, and minor spelling and grammar issues were corrected for readability. Quotations are identified by participant's pseudonym and age.

3. Results

3.1. Survey and focus group participant characteristics

One hundred fourteen teens participated in the online survey. Survey participants were on average 18 years old (range 13–19). The majority of survey participants self-identified as White (84%) and non-Latina (88%). Participants reported having a variety of seizure types and almost all reported use of AEDs (Table 1).

Twenty-six participants took part in 12 online focus groups. Focus group participants were on average 19 years old (range 15–20)[a] and the majority self-identified as White (73%) and non-Latina (96%). As with survey respondents, focus group participants

[a] One participant was 19 at the time of recruitment and had turned 20 by the time of the focus group.

Table 1
Survey and focus group participant characteristics.

	Survey sample ($n=114$)	Focus group sample ($n=26$)
Age, mean (range)	18 (13–19)	19 (15–20)
Ethnicity, *n* (%)[a]		
Latina	11 (11)	1 (4)
Non-Latina	88 (89)	25 (96)
Race, *n* (%)[a,b]		
American Indian or Alaskan native	7 (6)	0 (0)
Asian	3 (3)	0 (0)
Black or African American	6 (5)	1 (4)
Native Hawaiian or other Pacific Islander	1 (1)	1 (4)
White	100 (84)	19 (73)
Other	2 (2)	3 (12)
Seizure type, *n* (%)[a,b]		
Convulsive	46 (41)	8 (31)
Non-convulsive	29 (26)	3 (12)
Both convulsive and non-convulsive	31 (28)	14 (54)
Unsure	5 (5)	1 (4)
Use of epilepsy medication, *n* (%)[b]	97 (87)	15 (58)
Sexually active, *n* (%)[b]	66 (57)	15 (58)
Contraception use, *n* (%)[a,b]		
Intrauterine devices	4 (4)	2 (8)
Implant	3 (3)	0 (0)
Shot	7 (7)	5 (19)
Vaginal ring	3 (3)	0 (0)
Patch	3 (3)	1 (4)
Oral contraceptive pills	50 (49)	12 (46)
Male condom	54 (52)	0 (0)
Female condom/cervical barriers	1 (1)	17 (65)
Fertility-based awareness methods	0 (0)	1(4)
Emergency contraception	9 (9)	5 (19)
Withdrawal	23 (22)	2 (8)
Foam/jelly/cream	1 (1)	1 (4)
Never use	33 (32)	7 (27)
Been pregnant	4 (4)	4 (15)

[a] Missing responses.
[b] Participants could select more than one response; percents may not add up to 100.

reported having a variety of seizure types and almost all reported use of AEDs (Table 1).

3.2. Contraceptive use

Over half of survey and focus group participants reported being sexually active. The majority of survey and focus group participants reported having used contraception. Survey and focus group participants indicated use of a variety of contraceptive methods, most commonly oral contraceptive pills (Table 1).

Sixty-five percent of survey participants reported their primary reason for using contraception was pregnancy prevention. Survey participants also commonly related using birth control to experience non-contraceptive benefits, including period regulation (61%) and reduction of menstrual cramps and pain (45%) (Table 2). Focus group participants reported using contraception for similar reasons and that they considered the specific features of methods when making contraceptive decisions, including the mode of delivery, effectiveness, duration of effectiveness, accessibility, and affordability.

Table 2
Contraceptive experiences among survey participants.

Overall sample[a]	$n=75$
Reason for using contraception, *n* (%)[b,c]	
Preventing pregnancy	49 (65)
Regulating period	46 (61)
Reducing cramps/pain	34 (45)
Preventing STIs/STDs	25 (33)
Treating acne	18 (24)
Reducing seizures	9 (12)
Other	4 (5)
Treating endometriosis	3 (4)
When I first went on birth control…[b]	
I felt unsure about what to do, *n* (%)	
Yes	16 (23)
No	52 (74)
Unsure	3 (4)
I was worried what could go wrong, *n* (%)	
Yes	37 (53)
No	32 (46)
Unsure	1 (1)
I changed my mind a lot about which birth control method to use, *n* (%)	
Yes	20 (29)
No	48 (69)
Unsure	2 (3)
I changed my mind a lot about whether to be on birth control, *n* (%)	
Yes	19 (27)
No	50 (71)
Unsure	2 (3)
I delayed picking a birth control method, *n* (%)	
Yes	12 (17)
No	57 (81)
Unsure	2 (3)
I delayed starting birth control, *n* (%)	
Yes	13 (19)
No	57 (81)
Unsure	1 (1)
Changes in seizures while using contraception, *n* (%)[b]	
Yes	13 (17)
No	43 (57)
Unsure	19 (25)
Type of changes in seizures while using contraception, *n* (%)[b,c]	
Decreased frequency of seizures	6 (46)
Increased frequency of seizures	5 (39)
Decreased severity of seizures	4 (31)
Increased severity of seizures	2 (15)
Changed type of seizure	1 (8)
Unsure	1 (8)
Other	1 (8)
Type of contraception used when experienced changes in seizures, *n* (%)[c]	
Intrauterine devices	0 (0)
Implant	1 (8)
Shot	3 (23)
Vaginal ring	0 (0)
Patch	1 (8)
Oral contraceptive pills	7 (54)
Male condom	4 (31)
Female condom/cervical barriers	0 (0)
Fertility-based awareness methods	0 (0)
Emergency contraception	0 (0)
Withdrawal	2 (15)
Foam/jelly/cream	0 (0)

[a] Number reporting contraceptive use.
[b] Missing responses.
[c] Participants could select more than one response; percents may not add up to 100.

3.3. Knowledge and perceptions of interactions between AEDs and contraception

The majority of survey participants indicated that AEDs could reduce the efficacy of hormonal contraceptives (71%) (Table 3). Focus group participants shared similar beliefs, with many stating something similar to what Natalie, age 15, said: that her "medicine interferes with birth control." Additionally, the majority of survey participants reported that interactions between hormonal contraceptives and AEDs could increase seizure activity (66%) (Table 3). A

Table 3
Contraceptive knowledge among survey participants.

Overall sample	$n = 104$
Some epilepsy medications make birth control less effective, *n* (%)	
True	74 (71)
False	1 (1)
Unsure	29 (28)
Some types of birth control can lead to an increase in seizures, *n* (%)	
True	69 (66)
False	5 (5)
Unsure	30 (29)
Some types of birth control can help reduce seizures, *n* (%)	
True	33 (32)
False	25 (24)
Unsure	46 (44)

similar theme emerged in focus groups; many participants reported that hormonal contraceptives could affect their medication and "make seizures go nuts" (Megan, age 19).

Further, survey and focus group participants often expressed that the outcome of medication interactions was not only reductions in contraceptive efficacy *or* seizure control, but reductions in *both*. In write-in responses, survey participants stated that hormonal contraceptives and AEDs generally "clashed" or "cancel[ed] each other out." One focus group participant summed the issue up saying: "Not only would the birth control affect the medicine, but vice versa. Basically, I'd end up seizing and pregnant" (Lauren, age 19).

There was also a notable amount of uncertainty about the above issues. Close to one-third of survey participants were unsure if AEDs render contraceptives less effective, 29% were unsure if contraceptives increase seizures, and 44% were unsure if contraceptives reduce seizures (Table 3). Confusion about interactions also emerged in the focus groups. One participant explained, "[I'm] clueless/unsure what does birth control actually DO to cause seizures" (Amy, age 15).

3.4. Epilepsy-related contraceptive experiences

Few study participants reported experiencing reductions in contraceptive efficacy while using AEDs and hormonal contraceptives. Only four survey participants reported having experienced a pregnancy and indicated they were either not using contraception or a hormonal method at the time of pregnancy. Similarly, only four focus group participants reported having ever been pregnant. However, a small number of focus group participants reported experiencing signs of reductions in contraceptive efficacy due to medication interactions. One participant related: "My OB/GYN told me over and over that it [birth control] wouldn't interfere [with AEDs]. . .. I had a pregnancy scare twice. . .. It turned out my meds decreased the chances of them working" (Megan, age 19).

A minority of study participants reported that medication interactions affected their seizures. Seventeen percent of survey participants reported experiencing changes in seizures while on contraception and most reported using oral contraceptive pills when seizure changes occurred. No clear pattern emerged about how seizures were impacted, as some participants reported their seizure activity both worsened and improved (Table 2). Only a minority of focus group participants experienced changes in seizure occurrence while using hormonal contraception. These participants were using a variety of hormonal contraceptives and most reported they experienced an increase in seizures.

3.5. Role of epilepsy in contraceptive decision-making

Concerns about medication interactions influenced participants' contraceptive decision-making. When first starting contraception, the majority of survey respondents reported they worried about what could go wrong (53%) (Table 2). During focus groups, participants described contraceptive decision-making as an involved process complicated by their perceptions that no particular contraceptive method works best for people with epilepsy. Further, focus group participants reported that identifying the appropriate combination of contraceptives and AEDs required undesired trial and error. One participant explained, "It takes a while to find one [a contraceptive method] that fits you as a female, and on top of that, one that is gonna work with our meds" (Haley, age 18).

A third of survey participants reported that epilepsy impacted their decision to initiate contraception and impacted the type of contraception they use (Table 2). When asked to explain how epilepsy influenced their contraceptive decisions, survey participants responded that they avoided hormonal contraceptives out of fear of how the medications would interact. Similarly, some focus group participants reported avoiding hormonal contraception altogether and said they relied on non-hormonal methods to avoid any impact on seizures: "My boyfriend and I have been together for about a year and, while we would really like for me to be on a hormonal birth control, we both agree we'd rather not take the chance of a seizure" (Lauren, age 19).

3.6. Health care providers as contraceptive decision supports

Forty-one percent of survey participants reported that a doctor had talked to them about contraception. Among these participants, 83% reported having discussed contraception with an epilepsy specialist, 44% with a women's health care provider, and 42% with a primary care provider (Table 4).

During focus groups, some participants reported having discussed contraception with a doctor. For these participants, health care providers, and particularly epilepsy specialists, emerged as key resources when considering, starting, stopping, or changing contraceptives. Generally, focus group participants reported satisfaction with the contraceptive counseling they received. However, they also related that discussions with health care providers about contraception were limited in scope and centered on the importance of preventing unplanned pregnancy because of the risks that an unplanned pregnancy can pose to someone with epilepsy and their fetus. One participant explained, "I've mostly heard [from my doctor] about actually getting pregnant and the way the meds [AEDs] can cause birth defects" (Kelsey, age 19). Focus group participants desired more in-depth counseling and expressed frustration with their doctors' lack of communication regarding the interactions between contraception, AEDs, and seizure control. One participant explained, "Well, my doctors never said much about sex. . .. I was never told if it was okay to take birth control or if it would mess with my meds or seizures. I was so confused" (Megan, age 19).

In addition, some focus group participants reported they were given incorrect information about both general and epilepsy-specific contraceptive issues from their doctors, which interfered with their abilities to make informed contraceptive decisions. A small number of participants pointed to poor guidance from providers as a key factor that led to an inability to take advantage of the non-contraceptive benefits of birth control, or loss of seizure control and unplanned pregnancy. Further, a few participants

Table 4
Health care provider and parental involvement in survey participants' contraceptive care.

Overall sample	$n = 104$
Talked to a doctor about birth control or pregnancy prevention, *n* (%)[a]	
Yes	42 (41)
No	55 (53)
Unsure	6 (6)
Type of doctor talked to about birth control or pregnancy prevention, *n* (%)[a,b]	
Specializes in epilepsy	34 (83)
Specializes in women's health	18 (44)
Regular doctor	17 (42)
I wish a doctor would tell me more about birth control for women with epilepsy, *n* (%)[a]	
Yes	53 (52)
No	28 (27)
Unsure	21 (21)
How often is parent/guardian in room when talk to doctor about birth control, *n* (%)[a]	
Always	20 (49)
Sometimes	11 (27)
Rarely	6 (15)
Never	4 (10)
When I/If I go to the doctor for information about birth control, I wish my parent/guardian would. . ., *n* (%)[a,b]	
Come with me into the doctor's office	60 (57)
Stay in the waiting room	45 (43)
Drop me off at appointment, but not come inside	8 (8)
Not be involved at all	19 (18)
Unsure	3 (3)
Received information about birth control or pregnancy prevention from parent/guardian, *n* (%)[a]	65 (63)

[a] Missing responses.
[b] Participants could select more than one response; percents may not add up to 100.

described scenarios in which they were given conflicting information about contraception from their doctors:

> I have 2 doctors I see for epilepsy. . .and they both have different feelings about it. The neurologist thinks I should just use condoms. . .because he thinks that it [the pill] will change my hormones. . .and the epileptologist thinks I should get on it [the pill] so I don't get pregnant. I don't know (Jennifer, age 18).

3.7. Parents as contraceptive decision supports

The majority of survey participants (76%) reported that a parent was always or sometimes in the room when they talked to their health care providers about contraception and that they generally preferred parents being involved in their contraceptive appointments (57%). Further, 63% of participants reported having received information about contraception from their parents (Table 4).

Like survey participants, most focus group participants reported having discussed contraception with their parents and described their mothers, in particular, as important sources of contraceptive support. Teens reported a parent helped them understand how contraceptives might impact their epilepsy or other health concerns, such as polycystic ovary syndrome [PCOS]. Parents were described as important advocates who asked doctors questions about epilepsy and contraception that teens might not have known to ask or felt comfortable asking. One participant explained, "I feel completely comfortable with her [mother] there [in the doctor's office]. She highly pushed for it [birth control] after my PCOS diagnosis. . .. but I wouldn't have been as aggressive about it because I'm shyer" (Rebecca, age 19).

Focus group participants' comfort with parental involvement in their contraceptive decisions seemed to stem from being used to having their parents involved in their epilepsy care, and because they were on their parent's insurance. One participant explained,

> I rely on my parents a lot, and need them to be filled in with all of the information the doctor is giving me. There haven't really been times when I've wanted them out of the room while talking to the doctor. I need my parents there, it's me and them fighting my epilepsy. It's easier with my parents there. (Monique, age 19)

Although parents were often involved in focus group participants' decisions around contraception, teens emphasized that they saw their final contraceptive decision as their own. They also stressed the importance of confidentiality for other teens without supportive parents or who felt uncomfortable opening up to a doctor about sexual activity in front of a parent.

3.8. Participant recommendations for better contraceptive care

Most survey participants (52%) and focus group participants stated that they wished their health care providers would tell them more about contraceptive issues for females with epilepsy (Table 4). One focus group participant described her desire for more information: "I would like to have more resources on how birth control will negatively affect me as a person with epilepsy and how it will benefit. Maybe what the best brands are if you have seizures" (Megan, age 19).

In addition to wanting contraceptive information, focus group participants also reported a desire for more contraceptive support systems, as they felt often felt unsure of where to go for comprehensive information that addresses their specific contraceptive needs. One participant explained,

> I feel very uninformed. I wish my doctors would give me more information on the effects my medication plus birth control would have. I research it on the internet but sometimes the information just contradicts each other. I don't know anyone else with epilepsy so I have no one to ask" (Olivia, age 19).

Like the above participant, many other teens noted that outside of the online focus groups they had never talked to other teens with epilepsy. Teens commonly described having epilepsy as isolating and reported that it was powerful to communicate about epilepsy and contraception with others with epilepsy: "I thought the chat was therapeutic honestly. It's nice to talk to someone in the same boat as I" (Jennifer, age 18).

4. Discussion

The ability to make informed contraceptive decisions is important for teens with epilepsy as interactions between AEDs and hormonal contraceptives can lead to an increased risk of unplanned pregnancy and seizure occurrence, and because of the potential for some hormonal contraceptives to improve seizure control.[3,5,6,37] In this study, participants reported incomplete knowledge of and confusion surrounding the potential risks and benefits associated with taking AEDs and hormonal contraception. At the same time, participants described a number of concerns about hormonal contraceptive use that they felt made identifying an appropriate contraceptive difficult and severely limited their contraceptive options. These participants were often unaware or unsure about the potential for using hormonal contraceptives to improve seizure control. Taken together, these findings suggest that teens with epilepsy lack the appropriate information to make informed contraceptive decisions and that they often view using contraception as a risky endeavor.

The findings from this study highlight several avenues for better meeting the contraceptive needs of teens with epilepsy. First, while participants reported that health care providers are critical sources of contraceptive information, gaps in provider knowledge about contraceptive issues for teens with epilepsy appear to present barriers to high-quality contraceptive care, suggesting a need for guidance for providers offering contraceptive care to this population. Notably, existing guidelines from the neurological community on the reproductive health needs of females with epilepsy only address the needs of adult women and focus exclusively on pregnancy.[4] The 2010 release of the CDC's United States Medical Eligibility Criteria (US MEC), which offers guidance to health care providers offering contraceptive counseling to women with medical conditions and specific characteristics, represents a critical step toward addressing provider knowledge.[38] However, because the US MEC addresses a broad array of health conditions, it is limited in depth regarding the contraceptive needs of those with specific conditions. Specific in-depth guidance for health care providers supporting contraceptive decisions of teens with epilepsy is needed. Our results suggest that, at a minimum, this guidance should address both the broad benefits of contraception, as well as epilepsy-specific considerations, so that teens can make contraceptive decisions that best meet their health care needs.

Another method for ensuring the contraceptive needs of teens are met is to better educate and support teens themselves. The development of a contraceptive support tool for teens, based on existing evidence and findings from this study, has the potential to help increase teens' knowledge and empower them to advocate for the health care they want and need. Such a tool should consider the specific information gaps identified here, and would likely be most effective and acceptable if it incorporated peer support systems. Research suggests that peers are a main source of sexual health information for teens,[39] yet few teens in this study reported having ever talked to other teens with epilepsy. Given that teens with epilepsy have to navigate unique contraceptive challenges, in addition to the same contraceptive issues as other teens, providing this population with ways to share contraceptive experiences may help support teens as they navigate a myriad of contraceptive decisions. Finally, the tool should also include guidance for discussing contraceptive needs with health care providers and parents to help teens navigate an increasingly complex health care system.

This study has several limitations. First, the non-representative nature of the study population and self-selection of participants limits the study's generalizability. Study participants were on average 18 or 19 years old and findings may not be applicable to younger teens. Second, this study is subject to recall bias, as teens were reporting information based on past experiences. Despite these limitations, this study provides new, rich data on experiences of female teens with epilepsy. Further, findings regarding the challenges teens with epilepsy face accessing high-quality contraceptive care are consistent with those of adult women.[40]

5. Conclusion

This study found that female teens with epilepsy lack the necessary information and support to make informed contraceptive decisions which is troubling given that interactions between AEDs and hormonal contraceptives can lead to increased risk of unplanned pregnancy and seizure occurrence. Efforts are needed to better meet the contraceptive needs of teens with epilepsy. Findings from this study may also be useful for understanding how teens with other chronic conditions navigate contraceptive decisions. The use of prescription medications that affect contraceptive efficacy is common in the United States, though few people taking prescription medications receive adequate counseling about their impact on contraceptive efficacy.[41] Further, AEDs are often also used to treat mental health disorders, such as depression. Likewise, findings from this study are of relevance for other teens with chronic health conditions whose contraceptive needs may be unmet.

Conflict of interest

The authors have no conflict of interest to disclose.

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